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HIV provider experiences engaging and retaining patients in HIV care and treatment: “A soft place to fall”

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Abstract

Engaging and retaining persons with HIV in care and treatment is key to reducing new HIV infections in the United States. Understanding the experiences, barriers, and facilitators to engaging and retaining persons in HIV care from the perspective of HIV care providers could help provide insight into how best to achieve this goal. We present qualitative data from 30 HIV care providers in three cities. We identified three facilitators to HIV care: providing a medical home, team-based care and strategies for engaging and retaining patients in HIV care, and focus on provider-patient relationships. We identified two main barriers to care: facility-level policies and patient-level challenges. Our findings suggest that providers embrace the medical home model for

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engaging patients but need support to identify aspects of the model that promote engagement in long-term HIV care, improve the quality of the provider-patient relationship, and address persistent logistical barriers, such as transportation.

Keywords

barriers to HIV care; engagement in HIV care; facilitators to HIV care; HIV care providers; retention in HIV care

It is estimated that 1.2 million people in the United States are living with HIV, and about 45,000 new infections occur annually (Bradley et al., 2014). Of people living with HIV infection (PLWH), it is estimated that 87% have been diagnosed, and of those diagnosed, 75% were linked to HIV care within 1 month of diagnoses, 56% were engaged and retained in care, and 55% were virally suppressed (Centers for Disease Control and Prevention [CDC], 2016). Viral suppression, the end result of successful HIV care and treatment, leads to better health outcomes and lowers the risk of transmitting HIV to others (Bradley et al., 2014; CDC, 2011; Cohen et al., 2011; Cohen et al., 2016; Skarbinski et al., 2015). The *National HIV/AIDS Strategy: Updated to 2020* (Office of National AIDS Policy, 2015) focused national HIV prevention resources on treatment as prevention, a strategy to reduce rates of HIV transmission through competent and responsive HIV care and treatment for all PLWH. The success of the treatment-as-prevention strategy has been measured along the HIV care continuum, a linear depiction of stages of care from HIV testing and initial diagnosis, linkage to care, engagement and retention in ongoing care, adherence to antiretroviral therapy (ART), and viral suppression (Cheever 2007, Gardner, McLees, Steiner, Del Rio, & Burman 2011). To be considered successfully engaged and retained in HIV care, PLWH must attend two annual care visits that include documented CD4+T cell count or viral load testing (CDC, 2016). Unsuccessful engagement in care is associated with delays in ART initiation, poor adherence to ART, greater morbidity and mortality, and ongoing HIV transmission risk (Gardner et al., 2011; Giordano et al., 2007; Mugavero et al., 2009; Ulett et al., 2009).

Significant social disparities impact how PLWH access and engage in HIV care and treatment. Black/African American and Hispanic/Latino PLWH are less likely than Whites to be linked to care, receive ART, or be virally suppressed (Cohen, Hu, Sweeney, Johnson, & Hall 2014; Hall, Frazier et al., 2013, Hall, Tang, Westfall, & Mugavero, 2013; Wohl et al., 2011). Black men who have sex with men (MSM) are more likely than White MSM to present at a late stage of HIV, are more likely to experience barriers to HIV care, and are less likely to be offered ART, adhere to ART, and be virally suppressed (Cohen et al., 2014; Hall, Frazier, et al., 2013; Hall, Tang et al., 2013; Millet, 2013; Millet et al., 2012). Many PLWH have been affected by poverty, unemployment, substance dependence, and mental health issues; lack health insurance; are unstably housed; lack transportation; and experience or perceive the negative impact of HIV-related stigma on their health seeking behavior (Beer, Fagan, Valverde, & Bertolli, 2009; Bradford, 2007; Eaton & Kalichman, 2014; Eldred & Malitz, 2007; Gill & Krentz, 2015; Horstmann, Brown, Islam, Buck, & Agins, 2010;

McNairy & El-Sadr, 2012; Mugavero, Norton, & Saag, 2011; Naar-King et al., 2007; Rumpitz et al., 2007; Sohler et al., 2007; Wohl et al., 2011; Yehia et al., 2015).

Successful patient engagement and retention in HIV care has been facilitated by (a) enhanced personal contact with providers (Gardner et al., 2014) and patient trust in physicians, including perceptions of provider respect (Dang, Westbrook, Black, Rodriguez-Barradas & Giordano, 2013; Graham, Shahini, Grimes, Hartman, & Giordano, 2015; Maulsby et al., 2015; Yehia et al., 2015); (b) intensive case management to alleviate disparities and increase access to care providers (Bradford, 2007; Maulsby et al., 2015; Mugavero, Amico, Horn, & Thompson, 2013); and (c) housing assistance to improve access to health care and use of health care services (Wolitski et al., 2010). Enhancing provider communication, including increased empathy for the experiences of patients that influence care, better listening skills, and cultural competency can positively impact engagement and retention in HIV care, including keeping appointments and adherence to ART (Christopoulos et al., 2015; Flickinger 2013, 2016; Saha 2010). Despite challenges, it is widely believed that treatment as prevention offers the greatest potential to alleviate disparities in HIV care and treatment, increase engagement and retention of PLWH in ongoing care, achieve viral suppression, and reduce national rates of HIV transmission (Cohen et al., 2014; Das et al., 2010; Gardner et al., 2011; Mugavero et al., 2011; Skarbinski et al., 2015).

Existing literature has identified the extent to which social disparities and other barriers affect HIV care, as well as strategies required by HIV care providers to fully engage and retain patients in care. Much of what is known about challenges in HIV care and treatment is from the perspective of PLWH and their struggles to successfully engage with the HIV care continuum. There is, however, a growing body of literature on the role of providers in engagement and retention of patients in HIV care and treatment, making provider perspectives important to the overall success of a treatment as prevention strategy. This study attempted to explore barriers and facilitators experienced by providers related to engaging and retaining their patients in HIV care to: (a) identify challenges and successes experienced by providers, and (b) identify opportunities to further support HIV care providers in successfully engaging and retaining PLWH in HIV care and treatment.

Methods

Between July and September 2013, we conducted a qualitative study with 30 HIV care providers. Our intent was to understand the facilitators and barriers experienced by providers in their efforts to engage and retain patients in HIV care and treatment. Providers were defined as: physicians, physician assistants, clinical nurse specialists, nurse practitioners, or other health care professionals certified in his or her jurisdiction to prescribe ART; and case managers or social workers who support clinical staff. All participants provided voluntary informed consent. Study procedures were approved by the Abt Associates, Inc., Institutional Review Board.

Eligibility and Recruitment

Participant recruitment consisted of a three-step eligibility process: (a) selection of cities based on HIV incidence ($n = 3$), (b) selection of facilities ($n = 9$), and (c) selection of providers within each facility ($n = 30$, 3–4 providers per facility). We targeted three Metropolitan Statistical Areas (MSAs) with high incidence and prevalence of HIV: Atlanta, Georgia; Baltimore, Maryland; and Washington, DC. In 2013, Baltimore, Atlanta, and Washington, DC ranked fourth, fifth, and sixth in the United States in terms of rates of diagnoses of new infections, respectively (CDC, 2015). Approximately 10% of all newly diagnosed infections in the United States in 2013 were among persons living within these three MSAs. Further, all three MSAs had a high number of individuals living with diagnosed HIV infection. Within each of the three MSAs, we identified a sample of HIV health care facilities based on three sources: (a) past partnerships with local facilities (on previous studies), (b) searches in the Health Resources and Services Administration (HRSA) Ryan White HIV/Care provider website in each MSA, and (c) listings on the HIV Medicine Association within city catchment areas. To aid in narrowing our selection to three facilities per location, we developed a set of site selection criteria and prepared facility profiles populated with publicly available details of each site, including number of patients served, public or private, Ryan White funding, estimated HIV cases in MSA, years in service, and patient demographics. In conjunction with the site selection process, we developed a set of provider selection criteria to aid in selecting three or four providers per facility: providers must have had at least 12 months experience providing HIV medical care and related services, and be employed at least 20 hours a week at the participating facility. Finally, we attempted to elicit diverse perspectives among provider types (for example, if a physician at a clinic had already agreed to participate, we attempted to recruit a nurse or case manager at that clinic to provide variety in responses). Facilities were approached and provided information about the study. If they agreed, we contacted providers directly, shared information about the study, and scheduled an appointment for the interview.

Procedures

We conducted in-depth semi-structured interviews and a brief quantitative demographic survey with each provider. In-depth semi-structured interviews were 30–60 minutes in length and were digitally recorded and transcribed. Semi-structured interviews were designed to elicit a narrative on barriers and challenges experienced when providing HIV care. Topics included provider experiences with the HIV care continuum, with emphasis on barriers and facilitators related to engaging and retaining patients in HIV care, and innovative practices used by providers to engage and retain patients in care. Interviewers were social scientists with experience conducting qualitative data collection. For our study, engagement in care was defined as a broad process of linking patients to providers and services and assisting patients in making and continuing to attend ongoing provider appointments.

Analytic Methods

After interviews were transcribed, all personally identifying information was redacted or removed. Transcripts were coded for patterns and themes present in the data using a

qualitative content analysis approach (Schreier, 2012). The coding process was facilitated by NVivo® qualitative data analysis software.

First, an initial codebook was developed based on issues related to engagement and retention in care that were commonly reported in the HIV care literature. Two qualitative researchers used the initial codebook to independently code a randomly selected subsample of three interview transcripts. Second, because the initial codebook did not fully reflect all the views of the providers in our sample, the coders discussed how to revise the codebook so that it included a set of codes and code definitions that accurately reflected the content of the transcripts (MacQueen, McLellan-Lemal, Bartholow, & Milstein, 2008). After finishing all needed revisions, the final codebook was developed, and the two coders assessed inter-coder reliability. Inter-coder reliability was achieved when 86% of codes had a kappa of at least .80 (a kappa value of 1.0 indicates perfect agreement). Remaining transcripts were coded using the final codebook. Descriptive statistics were compiled to describe the demographic characteristics of participants using SPSS® statistical software.

Results

Facility Characteristics

Thirty-five HIV care facilities were originally approached based on the eligibility criteria. A total of nine facilities agreed to participate in the study, three in each of the MSAs, including seven public, non-profit facilities receiving Ryan White funds (referred to as Ryan White facilities), and two private, for-profit facilities (referred to as Private facilities). Non-participating facilities cited lack of time or interest as the main reasons for refusal. In some cases, we were unable to reach facility directors to gain permission to approach providers. We attempted contact via telephone and email. If facilities remained unresponsive after 3 calls and emails, we moved on to a facility with similar characteristics. Of these facilities, eight were in urban locations and one in a suburban location. Descriptions of facilities by specific MSA are not reported here to maintain privacy and confidentiality of participants.

Participant Characteristics

HIV care providers were recruited from participating facilities based on provider type (we attempted to recruit a variety of providers per facility) and on their interest and availability. A total of 30 interviews were conducted with 11 physicians, 6 nurse practitioners/physician assistants, 3 registered nurses, and 10 case managers/social workers. The sample included 6 providers from private facilities and 24 from Ryan White facilities. Our sample of providers were 80% White, 63% female, and at least a third were within 5 years of initial employment by their facilities. At least 50% of the sample were younger than 44 years with only 20% older than 55 years (Table 1).

Barriers and Facilitators

Providers commonly described three factors they believed were especially helpful to their efforts to ensure that their PLWH clients were engaged and retained in care. These included: (a) Providing a medical home for patients by co-locating services for HIV, mental health, other health care needs, and financial assistance; (b) Using a team-based or case

management approach to patient care coupled with other organization policies, programs, and strategies to engage and retain patients in HIV care; and (c) Connecting with patients on a personal level to foster respect and trust, where providers show empathy and interest in patients beyond their HIV care needs.

Providers reported two categories of barriers to engagement and retention: (a) Impediments related to the facility's operation or to broader system-level issues, such as long wait times for patients, large provider caseloads, staffing shortages, and poor integration of HIV care with other medical services; and (b) Patient factors that influenced successful and ongoing access and uptake of HIV care, such as overwhelming economic, social, and psychological need; the complexity of HIV care management; and housing instability, lack of transportation, and lack of reliable contact information for following up with patients at risks of dropping out of care.

Offering a medical home—The most common method mentioned by providers to engage and retain patients in HIV care was to co-locate essential HIV-related services and assistance programs in one facility, creating a medical home for PLWH, also known as a one-stop shop or providing wrap-around services. Providers were concerned about creating a supportive and caring medical environment for patients or, as described by one Ryan White facility case manager, offering patients a “soft place to fall.” Offering a variety of medical and social services in one location eased the transition of patients into care, especially if they required financial or insurance assistance and mental health or substance use treatment services. These core services were offered by most of the facilities in our sample. In addition, providers added services to their portfolios as they identified needs, such as onsite pharmacists and dieticians, or partnering with onsite or conveniently located primary care practices:

Something that stands out about this facility is the kind of holistic approach and the treating the whole patient and providing all of the different social services, dieticians. In fact, I just met with a newly diagnosed patient today, it was just awesome! Because she had met so many people in the building it wasn't just her doctor. (Physician, Private Facility)

This sentiment was echoed by a nurse practitioner in a Ryan White facility, “...so that they really get the sense that it is a home. It is a place where we'll provide a lot of different things.” The HIV medical home served as a place patients could receive services that were not essentially medical in nature, such as housing and transportation. These services were considered integral to engagement in HIV care:

I have success stories in helping people...not becom[e] homeless, helping clients for housing, rent assistance for months. [They] are taking care of [their] HIV medicines and they come in here, but they're looking for jobs and I'm able to help with that. Because if you're able to sustain help with rent assistance and housing, you're helping with HIV, as well... (Case Manager, Ryan White Facility)

The provision of non-HIV related services has been well established in Ryan White medical facilities, but was also highly valued as a successful model for engaging and retaining patients in private practice:

...But it's still necessary just because someone has insurance and can go to a private doctor's office doesn't mean they don't need those additional support services. So again, engaging the person holistically, addressing all of the different issues, all the barriers: financial, socio-economical, mental health, substance abuse. (Case Manager, Private Facility)

Using team-based approaches and other strategies—Providers frequently mentioned having strategies in place to identify persons at risk of dropping out of care, triaging services as needed, and regularly communicating as a patient-care team as essential for engaging and retaining PLWH in care. The benefits of team-based care were experienced as improving both the health outcomes of the patient and the care giving experience of the provider:

The different team members of the multidisciplinary team supporting each other is very helpful...I think the [pharmacist] does a really exemplary job, to be honest, in trying to help patients negotiate the pharmacy world, which is confusing, to say the least. So those are strategies to try and retain patients. (Physician, Ryan White Facility)

This was also expressed by private providers:

I just have the nurse that does that [identify patients at risk of dropping out of care] because we work as teams. So that's another thing that hopefully will help with retention too. Because the person has a contact person that they know to get a hold of ... And I think it's the team approach that really makes people feel like they know how to navigate the system because they know who to contact. (Nurse Practitioner, Private Facility)

Providers mentioned various strategies as a supplement to team-based care, including creating teams to address specific needs, such as adherence, mental health, or substance treatment. Some facilities also focused on care team communication strategies to identify patients at risk of dropping out through patient retention checklists, automatic appointment reminders, and patient contact systems that were activated once patients missed an appointment or were identified as being at risk of missing an appointment:

Yeah the process is easier when we all communicate. Usually once a week we have a clinical meeting and we discuss each client or if we have a problem with the client we all discuss it. And we try to figure out how to solve the problem together. (Case Manager, Ryan White Facility)

Connecting with patients—The third most frequent facilitator mentioned by providers was the importance of engaging patients on a personal level by showing they were sincerely trying to understand and empathize with their patients' life circumstances:

It's good to have that compassion and not lose that empathy, but I also think it's important to talk about the clients' dreams. I always tell my staff they've gone through a lot of things. They've survived a lot of stuff before they came to us and they will keep on surviving. (Case Manager, Ryan White Facility)

Providers described the importance of all staff adopting an accepting, engaging, and caring attitude with patients, not just the physician:

I believe that every staff person, whether it's the person at the front desk, the person who checks their blood pressure, the person that draws their labs, engages a patient, and so I across the board work with trying to instill a philosophy amongst all the staff in positive attitude, acceptance. People are not coming here to be treated like dirt. People come back here and we have great viral suppression rates because people are treated warmly. Because they don't feel judged or because we're not afraid to give a patient a hug or because we try to be friendly. So, I think having and supporting a staff that also fundamentally believes in this as opposed to this is not just a job this is almost more of a movement, a philosophy. (Nurse Practitioner, Ryan White Facility)

Facility-level barriers to engagement—Providers experienced multiple challenges implementing HIV medical homes. Inefficient policies, lengthy patient wait times for appointments, administrative pressure to shorten duration of appointments and see more patients in the allotted time, and insufficient staffing for team-based care coordination, case management and patient navigation activities were most frequently mentioned. A physician in a Ryan White facility stated, "...I just feel the whole flow is extremely slow and to some extent suboptimal...I assume if we had a lot more staff then a lot of people could be doing a lot of things."

Issues related to challenges managing staffing were considered barriers to patient engagement and retention in care:

It depends because we need more providers. So, sometimes they wait on the day of their appointment and they may wait a long time until they actually see the doctor...if they miss their appointment they often have to wait... So the next appointment is sometime down the road. (Nurse, Ryan White Facility)

When onsite services were not provided, providers experienced difficulties tracking referrals and monitoring patient engagement and retention in referred care. As a Ryan White facility case manager stated, "We don't have any control over [referrals]. That seems to be a barrier sometimes because people look back to us and say, 'Well, you said or you made this referral here and nothing has happened.'"

Patient barriers to engagement—Providers identified myriad patient needs and challenges they considered barriers to engaging and retaining patients in HIV care and treatment. While our sample of providers considered a medical home the most important strategy for engaging patients and addressing many patient-related challenges, providers said that a variety of barriers persisted and that their facilities could not easily address these problems. The most frequently mentioned challenges included economic instability of patients and lack of health insurance:

Well one barrier is insurance or lack of insurance. It's surmountable because they might be eligible for Ryan White funding but they have to apply for that, they have to bring documents, and sometimes they're not always prepared to do that or able to

do that. So that's a barrier. Sort of systemic barrier of insurance or not insurance.
(Physician, Ryan White Facility)

Providers were able to assist patients with navigation of public assistance programs. Despite this, patients faced extreme wait times, and other obstacles to obtaining assistance:

I would say one of the biggest things is getting people on ADAP [AIDS Drug Assistance Program] here. We have a rotating crew of people doing ADAP appointments, but it can be a several months wait to get the ADAP appointment...I think a lot of patients are frustrated that they can't start on medications right away.
(Physician, Ryan White Facility)

Many patient barriers were described by providers as overwhelming, requiring substantial facility resources:

Frankly, with the system as it is now, I feel overwhelmed trying to finish four patients in a half day. By the time you address substance abuse, mental health, safe sex, the list goes on and not to mention their asthma or any other health issue.
(Physician, Ryan White Facility)

In many cases, multiple health needs were complicated by poverty and homelessness. As a Ryan White facility Case Manager said, "If you're homeless you're not really going to care about being adherent to treatment. You're not going to care about taking care of yourself because you are just concerned with making it through the day."

Finally, many HIV care providers were frustrated by logistical barriers, such as missed appointments due to transportation issues:

We have the means to provide them with transportation but there's limitations. We do provide taxi and tokens. Very often the tokens are used for things... because they have other needs. So, trying to get them hooked up with transportation is probably a big one of barriers. (Case Manager, Ryan White Facility)

Unreliable contact information, including frequently changing phone numbers and addresses, created a barrier to engagement and retention in HIV care. Providers were frustrated by the substantial staff resources required to simply contact patients:

I can tell you that a good 50 to 60, to 70 even, percent of the phone numbers that I had for patients are not accurate. Either they're changed or maybe they don't have enough minutes when you call or it's been turned off. Whatever the reason is, it's not a functioning number. So, getting hold of patients is not a trivial matter.
(Physician, Ryan White Facility)

Providers expressed concerns that even in the context of a medical home and with provision of multiple social and medical support services, basic logistic challenges were frequently responsible for patients dropping out of care or receiving inconsistent HIV care and treatment:

The problems that I have is when I cannot contact them. Sometimes that happens. They come and say, "I'm ready to start again...I'm going to take my HIV medicines." And then they come for a week or two and then they disappear. They

give a phone number that they lost...Transportation because if they don't have the means to come here then they don't make it. (Case Manager, Ryan White Facility)

Overall, facilitators and barriers did not differ greatly between provider or facility types in our sample. Private facilities, although few in number ($n = 2$), were more likely to not have resources to coordinate care teams, hire case managers or social workers, or provide patient access to a wide range of onsite or referral services. In addition, private providers were more likely to see patients with insurance coverage and fewer needs for financial assistance. The majority of providers in our sample practiced in public health care facilities that received Ryan White funding ($n = 7$) and had access to a range of onsite support services, hospitals, and referral agencies.

Discussion

Of the 30 HIV care providers interviewed, we found almost unanimous support for and implementation of team-based and coordinated HIV care, enhanced provider-patient relationships, and provision of co-location of services as a medical home for PLWH. These were considered essential facilitators of successful patient engagement and retention in HIV care and treatment, even in private practices without access to Ryan White resources. Providers highlighted challenges implementing team-based care and providing onsite services, describing an array of patient and facility barriers, including unresponsive policies and procedures, inefficient systems, and administrative barriers resulting in heavy provider caseloads, long patient wait times, and inconvenient hours of operation. Similar findings related to the primacy of patient-provider relationships, holistic and coordinated care, and resource challenges were found in a qualitative study of Ryan White or affiliated medical facilities (Beane, Culyba, DeMayo, & Armstrong, 2014). Federal recommendations for HIV care clinicians have encouraged providers to become familiar with social disparities that impact patient access to needed services, build a skilled workforce for team-based care, improve service delivery, and provide patient navigation services for insurance to create a patient medical home (CDC, 2014).

From our interviews, and consistent with findings in the literature and federal guidelines, we identified three primary considerations for increasing patient engagement and retention in HIV care: (a) Identify and strengthen aspects of the medical home that positively impact patient engagement and retention in HIV care, (b) Support efforts to improve the quality of the provider-patient relationship, and (c) Implement low cost and novel solutions to logistical barriers.

Identify and Strengthen the Medical Home

Patient-centered medical homes mark a shift in how HIV care is provided, especially ramping up after provisions granted via the 2010 Affordable Care Act and support from federal agencies via the National HIV/AIDS Strategy (Office of National AIDS Policy, 2010; 2015) and HIV Care Continuum Initiative (Office of the Press Secretary, 2013). Originating in other medical settings, such as mental health care, the patient-centered medical home has been described as provider-directed, comprehensive, and coordinated care in a single location with a focus on patient and provider interactions (Kilo & Wasson, 2010).

Medical homes have been shown to reduce the cost of care and overall patient mortality (Grumbach & Grundy, 2010). Ryan White facilities have functioned as patient-centered medical homes for HIV care and treatment for more than 20 years and have been at the forefront of the medical home movement in HIV care. Little information is available on whether the medical home model improves long-term engagement and retention in HIV care, increases the likelihood of successful HIV outcomes, or reduces health disparities (Beane et al., 2014). Despite widespread adoption of patient-centered medical homes, there remain significant numbers of PLWH in the United States who experience significant challenges to continuous engagement and retention in HIV care (Mugavero et al., 2011).

Providers in our study were proponents of the medical home as an engagement and retention facilitator for PLWH. Most of the facilities in our study implemented coordinated, team-based care, core features of a medical home. This was true for both public sites receiving Ryan White funds (where we would expect to see this model implemented) and for private facilities. Limited resources, however, combined with the many needs of underserved and vulnerable patients, often forced facilities to reduce services. In one example, a provider described having to triage case management and navigation services to those at greatest need, while also understanding that those services would help all patients. Another suggested integrating HIV care with primary care or specialized care for other diseases such as hypertension or diabetes, to better meet the long term needs of PLWH. Challenges to integrating HIV care with primary care and alternative care models that incorporate chronic HIV care and primary care have been proposed but not widely adopted (Chu & Selwyn, 2011; Gottlieb, 2009).

Further research could identify the aspects of medical homes most critical in engaging and retaining PLWH over the long term (Beane et al., 2014). To this end, we must recognize non-linear HIV care, especially over time. Cyclical patterns of engagement in care, which include periods of dropping out of care, have been observed in patients over a period of years (Rajabium et al., 2007). In our sample, providers described patients moving in and out of care based on life events, to deal with competing health issues such as substance use treatment, or when feeling healthy. The public health goal of HIV elimination has encouraged a strong emphasis on early and ongoing care, even when PLWH feel otherwise healthy (Bertolli et al., 2013), but this may not be sustainable over a lifetime. Strengthening providers' abilities to engage patients across periods of intense HIV management and periods of health maintenance could use patient self-management strategies, increase use of telemedicine approaches, improve efficiency of service provision, and promote coordination of specialized HIV care with primary care.

Improve the Quality of the Provider-Patient Relationship

Providers in our sample perceived creating mutually respectful relationships between providers, staff, and patients as essential to engagement and retention. This included patient access to providers via telephone and text, allowing providers to directly communicate with patients outside of operating hours, and fostering a caring, non-judgmental philosophy toward patients. Patient trust in providers has been associated with increased patient satisfaction with care (McCoy, 2005) and improved retention in care (Dang et al., 2013;

Graham et al., 2015; Kempf et al., 2010). Patients want providers who connect with them, validate them as individuals, and partner with them to optimize their HIV care (Mallinson, Rajabium & Coleman, 2007). In contrast, negative experiences with providers have been associated with unsuccessful engagement in HIV care (Stutterheim et al., 2014). Case managers, social workers, nurses, and other staff described the importance of their roles in creating a caring environment, especially when patients needed more attention and time than available in the constraints of a typical 15-minute medical appointment. Providers expressed the desire to have more time to build relationships with patients and help them understand complexities of long-term HIV care and treatment. Interventions enhancing provider contact have been demonstrated to improve PLWH retention over time (Gardner et al., 2014). Supporting providers in their efforts to create mutually beneficial patient-provider relationships, such as tailoring trainings to specific patient needs and building staff capacity, or promoting policies, programs, and models that work to engage specific populations, could improve overall patient engagement and retention in HIV care and better health outcomes.

Implement Low Cost and Novel Solutions

Logistical barriers that impede patient engagement and retention in care were frequently discussed by providers. These included the lack of transportation to and from facilities, inconvenient hours, and inaccurate contact information for following up with patients. Providing ancillary services, such as transportation, has been a frequently cited strategy, but the evidence of its positive influence on engagement and retention is mixed (Andersen et al., 2007; Messeri, Abramson, Aidala, Lee & Lee, 2002). However, it is consistently identified as a barrier by patients in studies on barriers and facilitators to HIV care (Kempf et al., 2010). Where feasible, strategies to provide patients at greatest risk of dropping out of care due to limited access to transportation could be considered, such as opening on evenings and weekends and providing transportation options or community-based care.

Following up with PLWH who frequently change their contact information was time consuming and frustrating for many of the providers in our study. Providers found ways to contact people using innovative solutions, such as contacting PLWH through pharmacists, who could remind them to make appointments or update their contact information when they picked up medication refills. This strategy complemented other efforts to include pharmacists in HIV care, especially to provide adherence counseling or outpatient care visits (Horberg, Hurley, Silverberg, Kinsman, & Quesenberry, 2007; Penn, Watermeyer, & Evans, 2011). Formal utilization of pharmacists in patient engagement and retention efforts were supported by providers in our study and could reduce facility burden, address structural barriers, and improve overall patient engagement and retention in HIV care.

Limitations

There were several limitations to this study. With a small sample of 30 HIV care providers from 3 MSAs, our findings are not generalizable to a wider population. They may, however, be transferable, with or without modification, to other provider populations in other social contexts. An additional limitation is that we have presented the issues solely from the experiences and perspectives of HIV care providers. To fully understand barriers and

facilitators to care, it may be advisable to take into considerations the experiences and perceptions of PLWH and other stakeholders (e.g., insurer administrators, governing bodies).

Conclusions

HIV can be an overwhelming and complex diagnosis, especially for economically disadvantaged and/or marginalized persons, who may have limited or even negative experiences navigating health care systems and services. Our findings suggest that it is important to continue to develop and evaluate strategies and interventions that support providers in their efforts to engage patients in HIV care, including developing innovative facility-based policies and partnerships, and strong team-based, patient-centered HIV care. It is also critical to understand which aspects of patient-centered medical homes are most likely to influence sustained ART adherence and viral suppression. Bringing additional research to how engagement and retention in care works in practice, and how it can be supported and improved, may ultimately enhance efficiency of HIV care delivery, reduce staff burden, address structural and policy barriers, and increase the number of PLWH who are engaged and retained in HIV care.

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Key Considerations

- The medical home model is used by providers to increase patient engagement and retention in HIV care.
- The provider-patient relationship is an important component of patient engagement and retention strategies.
- Clinics can implement low-cost and novel solutions to address logistic and ancillary barriers to HIV care.

Table 1**HIV Provider Demographics**

Demographic Variable	Atlanta, GA	Baltimore, MD	Washington, DC	Total
Age (<i>n</i> = 29)	(<i>n</i> =10)	(<i>n</i> =10)	(<i>n</i> =9)	
25–34 years	2 (20%)	4 (40%)	3 (33.33%)	9 (31%)
35–44 years	3 (30%)	2 (20%)	1 (11.11%)	6 (20.7%)
45–54 years	3 (30%)	1 (10%)	4 (44.45%)	8 (27.6%)
More than 55 years	2 (20%)	3 (30%)	1 (11.11%)	6 (20.7%)
Ethnicity (<i>n</i> = 30)	(<i>n</i> =10)	(<i>n</i> =10)	(<i>n</i> =10)	
Hispanic or Latino/a	-	-	6 (60%)	6 (20%)
Non-Hispanic or Latino/a	10 (100%)	10 (100%)	4 (40%)	24 (80%)
Race (<i>n</i> = 29)	(<i>n</i> =10)	(<i>n</i> =10)	(<i>n</i> =9)	
Asian	-	1 (10%)	-	1 (3.4%)
Black/African American	3 (30%)	2 (20%)	-	5 (17.2%)
White	7 (70%)	7 (70%)	9 (90%)	23 (79.3%)
Gender Identity (<i>n</i> = 30)	(<i>n</i> =10)	(<i>n</i> =10)	(<i>n</i> =10)	
Female	5 (50%)	8 (80%)	6 (60%)	19 (63.3%)
Male	5 (50%)	2 (20%)	4 (40%)	11 (36.7%)
Years of Service at Facility	(<i>n</i> =10)	(<i>n</i> =10)	(<i>n</i> =10)	
< 5 years	3 (30%)	3 (30%)	4 (40%)	10 (33.3%)
6–10 years	2 (20%)	3 (30%)	2 (20%)	7 (23.3%)
11–20 years	3 (30%)	3 (30%)	1 (10%)	7 (23.4%)
> 20 years	2 (20%)	1 (10%)	3 (30%)	6 (20%)
Profession (<i>n</i> = 30)	(<i>n</i> =10)	(<i>n</i> =10)	(<i>n</i> =10)	
Physician	4 (40.0%)	4 (40.0%)	3 (30.0%)	11 (36.7%)
Nurse Practitioner	2 (20.0%)	2 (20.0%)	1 (10.0%)	5 (16.7%)
Physician Assistant	0 (0.0%)	0 (0.0%)	1 (10.0%)	1 (3.3%)
Registered Nurse	1 (10.0%)	1 (10.0%)	1 (10.0%)	3 (10.0%)
Case Manager/Social Worker	3 (30.0%)	3 (30.0%)	4 (40.0%)	10 (33.3%)

Note: Not all respondents provided data for all demographic variables